FACT SHEET

■ GLUTEN INTOLERANCE

This update for health care professionals is adapted from the May 1992 newsletter written by Elaine I. Hartsook, Ph.D., R.D., President and CEO of the Gluten Intolerance Group of North America.

Gluten-Sensitive Enteropathy (GSE) is a general term which includes the following disorders: Celiac Sprue, Dermatitis Herpetiformis and Transient Gluten Sensitivity.

CELIAC SPRUE

Celiac Sprue is the most common type of GSE. It is an inherited digestive disease. The protein in wheat, rye, oats, barley and other grains interact through an unknown mechanism involving the immune system to damage the mucosa of the small intestine. Celiac Sprue is frequently misdiagnosed as "irritable bowel syndrome." In some young women, the disorder may be misdiagnosed as an eating disorder. Although it is unknown who is at greatest risk for developing this disorder, children with Down Syndrome might be at an increased risk. Symptoms may include any one or more of the following:

- Diarrhea, excessive gas, abdominal pain or constipation or alternating diarrhea and constipation
- Weight loss or a history of low body weight despite excessive caloric intake.
- Chronic fatigue and weakness.
- Permanent tooth enamel defects.
- Irritability, inability to concentrate, and poor short-term memory.

Laboratory results or a medical exam may indicate the following:

- Chronic iron deficiency anemia which is not corrected by supplements.
- Laboratory values indicating nutrient malabsorption such as decreased serum carotene, folate, cholesterol, calcium, albumin and magnesium.
- Elevated circulating antibodies may help in screening and follow-up, but not diagnosis.
- Elevated liver enzymes, histological changes in liver tissue, decreased spleen size, gall bladder contraction, decreased pancreatic enzyme secretion and pancreatic insufficiency in children.
- Additionally, women with untreated celiac sprue have a higher rate of amenorrhea, spontaneous abortions and infertility.

Diagnosis

The majority of cases of celiac sprue are diagnosed in adulthood. The two-part diagnosis includes: 1. Small intestine biopsy and 2. Rapid response to a gluten-restricted, wheat-, rye-, oat-and barley-free diet. Strict, lifelong adherence to a gluten-restricted, gliadin-free diet is recommended.

DERMATITIS HERPETIFORMIS (DH)

DH is a glutensensitive hereditary disorder in which the primary lesion occurs in the skin. The lesions usually appear bilaterally as clusters of small, itchy water blisters on pressure points such as the knees, elbows and buttocks. DH is seen in children as well as adults. Diagnosis is made through both skin and intestinal biopsies. Although the lesions may be cleared by medications, a gluten-restricted, gliadin-free diet is recommended.

TRANSIENT GLUTEN HYPERSENSITIVITY (TGH)

TGH is extremely rare and is documented primarily in children under the age of two. Symptoms are similar to celiac sprue but there also may be acute symptoms, including shock, after gliadin ingestion. A gluten-restricted, gliadin-free diet is recommended. The syndrome seems to be self-limiting and those children eventually seem able to tolerate gliadin normally.

GLUTEN-RESTRICTED, GLIADIN-FREE DIET

Proteins found in wheat, rye, oats, barley, amaranth, quinoa, spelt and teff must all be avoided for persons who suffer from gluten sensitivity. Grains or starches that are allowed on the diet are: rice, corn, arrowroot, potato starch, soy flour and tapioca starch.

Dedication to label-reading is essential to the health of those with GSE. Ingredient listings, however, are also one of the major barriers. Problems are encountered, for example, in the different names under which the grains appear. For example, hydrolyzed vegetable protein, soy sauce solids and modified food starch may all be made with wheat. Malt flavorings may be made from barley.

These types of ingredients must be clarified with the manufacturer before a person with GSE should ingest them as even the smallest fraction of protein from the offending grains could cause illness and intestinal damage. Occasionally, grain-containing ingredients can be added to a product with no mention given in the ingredient listing. Also, some products may be labeled "gluten-free" yet still contain wheat, rye, oats, barley, etc.

Switching from a wheat-based diet to a rice or corn-based diet is an overwhelming challenge. One must be sensitive to the magnitude of this abrupt change and providing a coping strategy is extremely helpful to the client. Although the diet must be started immediately after diagnosis, some mechanism for the changeover must be supplied. Providing a thorough, up-dated diet instruction, a simplified meal plan, a list of manufacturers who provide special products, recipes and a list of support groups can be invaluable for a person with GSE.

OTHER COMPLICATIONS

Persons with GSE may also have additional food intolerances, the most common being lactose and soy intolerance, which are secondary to GSE. There also seems to be an increased incidence of malignant disease, especially non-Hodgkin's lymphoma as well as an increased incidence of decreased bone density. Other disorders known to be associated with celiac sprue include Type I insulin-dependent diabetes mellitus, Sjogren's Syndrome, Systemic Lupus Erythematosus, Addison's Disease, Grave's Disease, Autoimmune Chronic Active Hepatitis, Scleroderma and Myasthenia Gravis.

For further information, including a list of gluten-free foods, contact:

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